



## **Tactics of material participation**

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# Tactics of material participation: How patients shape their engagement through e-health

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## Abstract

The increasingly popular goal of ‘patient participation’ comes with a conceptual vagueness, at times rendering it an all-too flexible political trope or platitude and, in practice, resulting in unclear invitations to patients. We seek to open up the alluring yet troubling figure of patient participation, by inquiring into how patients enact participation in different ways. Based on close ethnographic engagement in a user test of the e-health system P-Record, we show how a group of heart patients shaped their participation along three lines of tactics of material participation: ‘activism’, ‘partnership’ and ‘compliance’. Our argument is twofold. First, we suggest that any invitation to participate carries the inherent paradox that, although certain ideas of participation may be materially embedded, e.g. in e-health or other ‘participatory technologies’, the enactment of participation cannot be foreseen. To participate is to creatively make do with the situation and technologies at hand, making participation normatively variable in practice. Second, we suggest seeing these normative variations as distinct, though interwoven, lines of tactics that bring about different expectations and, to different degrees, allow patients to handle ambiguous invitations to participate.

## Keywords

e-health, material participation, patient participation, tactics

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## E-health and the participatory turn

E-health systems have been given a leading role in facilitating new modes of patient involvement in care practices, and are instrumental in a 'participatory turn' in healthcare (Prainsack, 2011, 2014). E-health systems, here including patient-centred health records, on-line patient communities, telemedicine, health apps, etc., are said to be capable of disrupting longstanding relations of power and knowledge between healthcare providers and their patients (e.g. Dedding et al., 2011; Eysenbach, 2008). As a whole, these technologies are born out of and materialize the paradigmatic project of furthering the engagement of patients and citizens in practices and politics of healthcare. Patients' rights to and, not least, their resources for, active involvement in their own care and in the optimization of healthcare practices are tirelessly promoted – and increasingly by powerful institutions such as the state, the biomedical establishment, and industry (for examples in Danish contexts, see KMD, 2014; Regeringen, 2013; Sundhedsstyrelsen et al., 2012). Concepts like 'patient-centered', 'patient empowerment', 'patient involvement' and 'patient-driven' have become everyday parlance; they penetrate and seemingly unite democratic ideals, market models for service delivery, chronic care paradigms and innovation design narratives in healthcare (Fiore-Gartland and Neff, 2016). Patient participation seems to have become an almost ubiquitous strategy for improving healthcare in the twenty-first century and e-health is often seen as the lever for this strategy. However, 'patient participation' comes with a conceptual vagueness, at times rendering it an all-too flexible political trope or platitude and, in practice, resulting in unclear invitations to patients. For what is it exactly that patients are invited to participate in, in offers to become users of participatory technologies or to participate in the development of such devices? What does participation become, when conceived and orchestrated in the realm of technological innovation and public healthcare institutions? Recently a number of critical voices have called into question the participatory capacities of these technologies (Lupton, 2013) and the related participatory design or research processes per se (Bogner, 2012; Delgado et al., 2010; Irwin et al., 2013; Martin, 2008; Wehling, 2012). Wynne (2007: 100) has called for 'a better and more sceptical understanding of the seemingly positive turn' and Wyatt et al. (2013: 154) remind us 'not to confuse the potential for participation with what is currently happening'. It has also been suggested that the concept of participation has been co-opted by a booming industry of 'participation entrepreneurs' (Bogner, 2012), legitimating neoliberal responsibilization of users (Lupton, 2013) rather than giving patients actual voices in and political influence on individual and collective issues of care.

Where most attention is usually on how the invitation to participate is shaped by those inviting, in the realm of policies and discourse, this paper extends to the ways in which patients in practice respond to the invitation to participate. To us, the interesting question is not *whether* patients make active contributions to care – they clearly do, as repeatedly stressed by medical sociologists and others (see for instance Oudshoorn and Pinch, 2003; Strauss et al., 1985) – but rather *how* patients participate when participation is what is expected from them. We analyze a case of patient participation in e-health design in Danish heart care framed by initiators as participation in both (self-) care and technological innovation. The participatory technology in

question, P-record, is a patient-centered health record, enabling monitoring and communication among a diverse set of actors involved in the care of heart patients with an Implantable Cardioverter Defibrillator (ICD). With P-Record, the patient is to have a central role in managing the distributed public care regime involved when carrying an ICD. We seek to open up the alluring yet vague figure of patient participation by exploring the different ways in which these patients enact participation with P-Record. How do patients participate in the context of a 'participatory-minded' healthcare system and through devices and arrangements specifically made for instigating participation, in care and in innovation?

Analytically, we refrain from defining 'real participation', and identifying barriers and enablers hereof. However, we do not claim that participation 'just' happens, as if in spaces without power and resistance. On the contrary, we follow in line with other STS scholars (e.g. Felt et al., 2009; Marres, 2011; Sharon, 2015) who have argued for unfolding the relations of power in different engagement practices. Power does not have to mean the disciplining of subjects through dominant discourses of participative and 'healthy citizenship' (Sharon, 2015), but can equally concern the creative, partial or subversive ways in which people in practice engage when invited to participate. Suggesting the combined concept of *tactics of material participation* inspired equally by Marres (2012) and De Certeau (1984), we explore the creative ways in which patients in the user test of P-Record respond to the invitation to participate in research and in their own care. Following Marres (2012: 8), material participation points toward concrete situations where material entities are invested with capacities to mediate engagement, and the concept raises analytical awareness of the situated, material, normative and performative aspects of participatory practices. Drawing on De Certeau's (1984) concept of tactics, we want to suggest that, while carrying certain framings and conditions with them, the patients engage with such strategies in creative ways. Responses to the invitation to participate may be shaped by a variety of preferences, concerns, and previous experiences, as well as by the materiality of the technology in question. Tactics also connote a way of maneuvering in unclear territory, where local opportunities and challenges are handled *in situ* (De Certeau, 1984: xiii).

Our case reveals three situated tactics that we term *activism*, *partnership*, and *compliance*. As shall be demonstrated, these tactics involved different sentiments and produced different versions of the 'involved patient'. However, the patients' enactments of participation also, to some extent, shared a reorientation. While P-Record invited patients to participate both in their own care for the good of their own empowerment and treatment and in innovation for the good of society, the latter ended up being most important to the patients. As a political terrain, the encounter between P-Record and patients' participatory tactics seemed to support norms of engaging in collective projects more readily than norms of individual health projects.

## Theorizing participation

Past decades' political, technological, and organizational changes in Western healthcare seem to have paved the way for patient participation as a ubiquitous norm and governance strategy (May, 2010; Moreira, 2012; Prainsack, 2011). The wide scholarly interest

for patient participation has contributed to this development, often from a highly normative outset.

In social studies of medicine and applied healthcare research (e.g. Ashworth et al., 1992; Cahill, 1998; Cegala, 2011; Eldh et al., 2015; see also Collins et al., 2007 for an overview), patient participation has long been a central topic. The notion of participation is often closely linked to ideals of furthering shared decision-making in patient–physician interactions, with studies broadly sharing an ‘unease with paternalistic philosophy’ (Collins et al., 2007: 4) and a concern for the ‘persistence of asymmetry’ (Pilnick and Dingwall, 2011: 1374) in the clinical encounter. With a similar democratization agenda, an extensive body of literature explores and commits to different models of patient participation in research, such as participatory research (Cornwall and Jewkes, 1995), community-based participatory research (Minkler and Wallerstein, 2010), the dialogue model (Abma and Broerse, 2010), and patient-led research (Vayena and Tasioulas, 2013). A further body of literature has been promoting programs for patient participation in policy-making and service development (e.g. Boaz et al., 2016; Facey et al., 2010; Pizzo et al., 2015; Tierney et al., 2016). The emerging field of Participatory Medicine cuts across the arenas of care, research and policy-making and embodies the normative stance, as well as the persistent struggle of conceptualizing ‘participation’ (Barello et al., 2014; Gallivan et al., 2012; Kvedar and Kibbe, 2009). Across this otherwise diverse landscape, a number of scholars seek to define and measure levels of participation by drawing on classic conceptualizations such as Arnstein’s (1969) ‘ladder of participation’ or other formal criteria for dimensions of participation (e.g. Cahill, 1998; Eldh et al., 2010; Kelty et al., 2015; Thompson, 2007; see also Corrigan and Tutton, 2006).

Scholars in Science and Technology Studies (STS) have, from various vantage points, focused on empirical analyses of how patients actively engage in healthcare (Epstein, 2007; Rose and Blume, 2003) and increasingly are being mobilized as partners in healthcare activities from which they used to be excluded (Callon and Rabeharisoa, 2008; Langstrup, 2010; Van de Bovenkamp and Zuiderent-Jerak, 2015). In some instances, these descriptions of patients’ engagements have become part of normative prescriptions of increased public participation for furthering a democratization of healthcare (Brown and Zavestoski, 2004), maybe most notably in the field of e-health, where the participatory paradigm is additionally fuelled by user-centered design methodologies (e.g. Andersen, 2010; Clemensen et al., 2007; Pilemalm and Timpka, 2008; Storni, 2013; Unruh and Pratt, 2007). Importantly, while STS has invested in demonstrating and promoting (a more nuanced) public participation in science and technology at large, it has also, as Marres (2012) has noted, been unprepared to critically analyze the ‘rise to prominence of participatory approaches in these areas’ (p. ix). As Irwin et al. (2013) points out, STS may have offered critiques, in the sense of providing retrospective judgements of whether a specific participation initiative was good or bad, based on ideals of democratization of science, yet, this kind of principle-driven critique ‘can make it difficult to acknowledge and pay serious attention to the varieties of engagement that are very much less than perfect but still somehow “good”’ (p. 120). With the immense increase in participatory arrangements in healthcare and beyond, we agree that there is an urgent need to attend to ‘varieties of engagement’ in other and more nuanced ways than through post-hoc evaluations.

However, and despite this ‘blind spot’ in the field (Chilvers and Kearnes, 2016), STS offers sophisticated analytical tools for dealing with the roles of technological arrangements in social practices (Akrich, 1992; Latour, 1992), including participation (e.g. Chilvers and Kearnes, 2016; Hyysalo et al., 2016), and thus offers central resources for momentarily bracketing the advocacy for (and associated normative evaluation of) participation and turning the attention to participation as a multivalent, empirical phenomenon deliberately promoted and enacted through specific sociotechnical arrangements. This is where we start our conceptualization of participation.

## Tactics of material participation

Our concept of *tactics of material participation* draws on two different conceptualizations of how people engage with and through things in everyday practices: Marres’s (2012) concept of ‘material participation’, building on the material semiotics of actor-network theory and pragmatism, and De Certeau’s (1984) concept of ‘tactics’, anchored in a phenomenological tradition. We suggest that talking about tactics of material participation enables us to become sensitive to the agency of technology-users, while at the same time unpacking the materialized scripts of (political) participation that are becoming so central to contemporary society.

In her study of public participation in environmental issues, Marres (2012) deals with what she terms ‘material participation’ by looking at the roles of things in political participation. She draws on and contributes to an object-centred perspective in STS by bringing attention to the specificities and agency of those material entities already invested with expectations of enabling users to participate. Where actor-network theory makes the general point that material entities are always already implicated in shaping issues and practices, Marres (2012) sees ‘material participation as a *specific* phenomenon, in the enactment of which a range of entities all have roles to play’ (p. 2). Empirically, we can see that objects are given a very prominent role in contexts where citizens are invited to participate. As Marres (2012) points out, ‘[a] wide range of initiatives aimed at fostering public participation are explicitly designed to locate participation in material practices’ (p. 2). In healthcare, e-health technologies are examples of this. Rather than giving voice to ‘the missing masses’ of objects (Latour, 1992: 127), Marres’s project is to look at the situations where objects are operating in plain sight as levels of participation for human actors.

In light of this, Marres’s (2012) analytical goal becomes to ‘note the normative variations among enactments of material participation’ (p. 2). Participatory objects or technologies are multivalent: They do not determine particular participatory responses – their scripts are in the hands of later users, as the well-known doctrine of actor-network theory would have it (Akrich, 1992; Latour, 1992). It is an empirical question ‘how specific devices enable (or disable) the unfolding of spaces of participation’ (Marres, 2012: 27). The everyday situations at home, where people act with participatory technologies, are inherently ‘messy’: They involve a range of concerns, practices and devices that will influence how participation in this context is enacted (Langstrup et al., 2013; Pols, 2012). Moreover, there may already be vivid participation by humans and non-humans of kinds that are unrecognized by the institutions that call for more

participation, the question being ‘whether and how their contribution is acknowledged, framed and supported’ (Marres, 2012: 140). In our case, looking at the normative variations in how material participation is enacted implies attention to both the initial inscriptions and the actual uses of P-Record. Helping us conceptualize how users enact these normative variations in everyday practices and how they relate to issues of power, we suggest supplementing Marres’s perspective with the concept of ‘tactics’ taken from de Certeau.

As also suggested by Sharon (2015: 300), De Certeau’s (1984) concept of ‘tactics’ provides a useful alternative to conceptualizations of power that force us to focus either on the disciplining or liberating capacity of technology (see also Langstrup, 2013). In his exploration of everyday life, de Certeau suggests that users of products, technologies, physical structures, media and other aspects of ‘private life’ should be seen as actively and productively engaged in *tactics* – the creative ‘making-do’ with arrangements that are given to them. In de Certeau’s critical thinking, users’ tactics are inherently a form of opposition against the strategies imposed by elites and decision-makers in the form of, for example, physical structures and consumer products. Thinking in terms of strategies and tactics thus allows us to see how power is negotiated during the course of everyday life – the two are mutually constitutive, not oppositional, as Sharon (2015) also underlines (p. 301). This understanding of tactics has certain resonance with Akrich’s (1992) concept of de-inscription of technical objects in that Akrich also points to the underdetermined characteristics of technologies and the power – indeed necessity – of everyday users to translate original scripts (strategies in de Certeau’s terms) of any technology or material entity. De Certeau grants the material entities little attention, but the concept of tactics can supplement Marres’s object-oriented perspective with an empirical attention to how the normative variations of participation are carried out by users in the course of their everyday lives, and how this also concerns negotiations of power. Tactics of material participation, in our account, might be thought of as the relational – often creative – maneuvering of users and technologies in practice, rather than as intentional acts of defiance against a power hovering above.

From here, we set out to investigate the following questions: How do tactics of material participation unfold in the case of e-health for ICD-patients? Which norms and purposes are enacted, *vis-à-vis* the overall strategy of patient participation in healthcare?

## Methods

Empirically, the article is based on the first author’s involvement in the design of P-Record, with the user test as the pivotal event. Studying practices that are part of a user test basically means studying an experiment – a temporary situation created to simulate or ‘rehearse’ a potential future (Halse et al., 2010), in this case potential future communication practices between home and clinic, enabled by e-health, in ICD-care. However, the practices unfolding in the user test were also immediate practices of participation in research/innovation. The user test thus offers more than a glimpse into a potential future of participatory healthcare with e-health: It shows the situated ways in which patients already may enact participation. In other words, the user test is, at once, a lab and a field that together offers us the opportunity to explore variations and patterns of how patients

may and do respond to the much-heralded and increasingly ubiquitous participatory strategy in healthcare.<sup>1</sup>

The user test took place over the course of three months in the winter of 2012–2013, as the culmination of a five-year-long Danish design research project, Co-constructing IT & Healthcare (CITH, 2013). It involved six ICD-patients, two cardiologists and two technicians from a specialized ICD-clinic at a university hospital, and two cardiologists from the out-patient heart clinic at a local hospital. Throughout the user test, the first author, who joined the design research project in the last implementation phase, acted as facilitator. She thereby took an interventionist approach in the ethnographic fieldwork and served in a double sense as a ‘participation entrepreneur’ by inviting patients to *participate* in the rehearsal/shaping of new *participatory* healthcare practices. With the first author in this peculiar position, we have been particularly active in constructing our field, mobilizing participants and instigating practices: building the lab. Clearly this entails that we are partly responsible for shaping the invitation to which patients responded – an invitation that we, nonetheless, attempt to treat with a critical stance in this paper. As others have pointed out (Jensen, 2012; Zuiderent-Jerak, 2015), this intricate involvement with the field is increasingly becoming the reality for many STSers who find themselves becoming part of innovation projects as the ones who invite users. While it certainly poses challenges to remaining reflexive, an interventionist position like the one of the first author also has great heuristic affordances. It places the researcher right in the middle of the network and practices being studied and, in our case, offered countless opportunities to learn first-hand about the work that goes into introducing new technology and facilitating participation. As others have also shown, the practicalities and frictions that come with constructing and maintaining a field can be highly analytically productive (Winthereik et al., 2002; Zuiderent-Jerak and Jensen, 2007). In the analysis, we will further highlight the role of the first author as facilitator. For now, we will shortly sketch the concrete activities of the user test.

The first author recruited patients by phone and subsequently gave instructions of how to use P-Record in their homes. During the user test, patients used P-Record to prepare for three different appointments with the clinics: an in-clinic ICD follow-up, a remote ICD follow-up, and a consultation at the local hospital’s out-patient clinic. Between these appointments, all patients had telephone or e-mail contact with the first author regarding test activities or additional instruction. Participation in the user test was initiated and concluded with in-depth interviews. In all these activities, facilitation and fieldwork melted together, with the empirical material ultimately consisting of: 1) participant observation from test activities in home and clinic, documented by field notes and video recordings, 2) a total of twelve semi-structured interviews and a number of informal conversations with the participating patients, 3) two group interviews as well as informal conversations with the participating clinicians, 4) screen dumps of all entries made in P-Record, and 5) publications and project documents from the design phase.

In the following section, we elaborate on the test activities and material outline of P-Record as well as the design rationale and process behind P-Record. Together, these ‘strategic elements’ made up the invitation to participate that patient-users were presented with and are, therefore, the natural starting point.



## Designing participation

P-Record was created and presented to its users as a participatory device: through its material layout and practices of design and testing, it posed an invitation to participate and thus mediated an overall participatory strategy of modern healthcare. The invitation was characterized by: 1) framing participation as collaboration with clinicians in providing relevant information for self-management, 2) inscribing participation into the material design of the technology, and 3) blurring the line between participation in research and participation in care. We will lay out these characteristics one by one.

### *Participation as collaboration*

P-Record was born out of an ambition to handle several challenges in ICD-care. First, ICD-care faces a well-recognized challenge in contemporary healthcare: coordination of care distributed between various clinics and professionals. A central design goal was, therefore, to 'enable patients to easier become information couriers' and thus support patients to be collaborators who help 'bridge inter-institutional care' (Andersen et al., 2011b: 5), as the involved design researchers here put it in a research publication. Second, the use of remote monitoring of ICDs for an increasing number of ICD-patients in Denmark means that most in-clinic ICD follow-ups are replaced by remote follow-ups. In practice, this means that patients and health professionals rarely meet, and that patients in our study had little opportunity to contribute with their own knowledge as part of the monitoring and management of their disease. In order to 'reintroduce the patients as active participants into the telemonitoring setup' (Andersen et al., 2011a: 112), P-Record was designed to enable patients to provide written accounts of their own well-being and symptoms. Finally, part of the design ambition was to develop more efficient and cost-effective services, based on patient work. This was to be achieved by: 1) enabling patients to prepare for clinical encounters, and 2) supporting the patient as a self-manager, who keeps track of his or her own condition and takes appropriate action, independently of the clinic. In turn, this would make 'collaboration' possible, allowing patients to become 'reliable and valuable content provider(s)' (Andersen and Moll, 2010: 1), and enabled to produce information for themselves for self-management. Inscribed into P-record, these two different versions of collaboration – as content providers and as self-managers – rendered the invitation to participate fundamentally ambiguous, as shall be elaborated on below.

### *Technology as enabler of participation*

By translating the ambition to involve patients as collaborators and information providers into a web application, the design project tapped into the vision of 'IT as a means for achieving shared care and involving patients as resources in their own treatment' (Andersen, 2010: 151) – a vision that articulates the widespread association between patient participation and e-health technologies.

P-Record contained a preparation form, a medication list, a logbook, an e-mail function and a social network. In the user test, the first author (as facilitator) started

instructions with the preparation form and medication list. She stressed these two features as the ‘key functions’,<sup>2</sup> and thereby framed P-Record as a tool primarily to communicate with clinics concerning specific appointments – a framing that was in line with the design goal of supporting direct collaboration between patients and clinicians. Introducing the preparation form’s first and second parts about general well-being, the first author stressed the patients’ own assessments: ‘what the system invites is that you yourself decide what you would normally tell [the clinicians] when you are there [at the clinic]’, thereby framing the system as enabling patients to articulate their own perspectives. The preparation form’s third part contained predefined symptom categories – a formalization that was meant to ensure that patients provided ‘clinically useful information’; it was presented by the first author as ‘what the doctors have said they are interested in hearing about’. The last part asked patients what they ‘would like to talk about at the meeting’ and was framed by the first author (borrowing from the patient-centered rhetoric of the design project) as giving them ‘the opportunity to set the agenda’. In sum, with the preparation form, patients were invited to provide information in return for receiving better answers; participation came across as a mutually beneficial deal built on information sharing.

Two other main features – the logbook and the social network – materialized the part of the design ambition that stressed patients’ role as self-managers. Indeed, the logbook exposed the ambiguity of P-Record’s participatory capacity: During instructions and in the layout the logbook was framed both as ‘a resource for yourself’ and a tool to ‘give [the clinicians] a little extra background’, potentially making it unclear to users whether they were taking part in a shared or an individual project. Furthermore, the logbook clearly materialized the inherently open nature of an invitation to participate, as it was explicitly left up to the patients to decide ‘what feels relevant to write’, as the first author and facilitator put it. In contrast, the social network, where patients could share information, more unequivocally materialized the participatory paradigm’s stress on patient empowerment independent of contact with health professionals and, thus, extended the notion of participation further than the logbook.

### *The entanglement of research and care*

In addition to the material design of P-Record, the entanglement of research/design and care shaped the invitation to participate that patient-users were presented with. By being invited to a ‘rehearsal of the future’ (Halse et al., 2010), patients were assigned a dual participatory role: they were simultaneously invited to participate in their own treatment/care and in research informing design of technology for future care practices (Andersen, 2010). These two ‘spheres’ of participation were deeply interwoven from the outset. Rooted in a Participatory Design tradition, the overall project actively involved future users throughout its iterative process, where patients and clinicians were invited to become ‘co-designer[s]’ in a design process of ‘collaborative prototyping’ and ‘envisionment’ (Andersen, 2010: 151 – referring to Bødker and Grønbæk, 1992).

The user test constituted a participatory arrangement put in place with a dual and, at times, self-contradictory set of goals: to support the configuration of patients as users of the technology (Woolgar, 1990) and, at the same time, to study the ways in

which patients responded to the invitation to participate. Managing this dual set of goals characterized the first author's practice as participation entrepreneur, that is, her deliberate work as facilitator of making people into users of P-Record and research subjects. She, thus, had to handle one of the 'paradoxes of participatory practices' (Howcroft and Wilson, 2003): On the one hand, she tried to keep an open approach and not dictate use, but instead sketch possible use practices while underscoring the experimental nature of the test; on the other hand, on-going guidance and reminders made the user test a laboratory-like situation, in which participation was nurtured in a specific way to enable research.

In sum, the overall project, and especially the design phase, built on a consistent and reflexive ambition to support patient participation in order to improve collaboration and ultimately create better care. However, when materially embedded in P-Record and enacted within the context of the user test, this ubiquitously 'participatory project' came to involve an ambiguous invitation to participate. We presented patients with a soft structure, so to speak – one that by definition invited them to do things their own way, but nevertheless posed a prescription to take part. Moreover, signals were mixed regarding what they were to take part *in* – research or care practices, or at times just their 'own projects'.

## Enacting participation

Having presented the structuring invitation to participate, with P-Record as the device materializing this invitation and its inherent ambiguities, we turn to how patients met the invitation and enacted participation. We thereby shift focus from the strategic to the tactical side of material participation. Through exemplary cases, we unfold three participatory tactics. The three tactics cannot be delimited to their respective cases; to various extents, they are interwoven through all cases. However, we believe that each case exhibits one tactic in particular, and we foreground this tactic to be able to portrait its distinct features. In each case, we focus on situations from the user test that illustrate the dominant tactic. Background interviews provide a context for these situations.

### Activism

Anne is evaluating the social network function, browsing through the logbook of another patient, who has chosen to share this. She reads out loud: 'Dizziness, anxiety, panic attacks'. She sighs. 'If that's caused by the medication, then you should reassess it and give him something else. Those issues should make them find something else for that poor man. It's his whole life!' I ask her if she would write this to him if she could. Yes, she would ask him to talk to the doctors about it: 'You know, I can't help thinking a bit further when he writes about such big issues', she says. 'You feel like saying something to him – that he shouldn't put up with it, that he has to take it further'. (Field note, evaluation of the system with Anne)

In the situation above we meet Anne, an experienced ICD-patient and research participant. She enacts what we term an *activist* participatory tactic: her attitude throughout the user test, as well as towards her situation at large, is characterized by pragmatism and

low expectations, but also by an eagerness to experiment. She participates as a representative for other patients – with personal distance, but willingness to be actively involved, take on responsibility, and push for change.

*Critical pioneering.* During the recruitment for the user test, an alliance between Anne and the first author forms. They are both non-clinicians, critical of the existing communication practices and pragmatic about the system's potential. Yet they also share an activist's desire to make things better. Thus, and although posing an open invitation, the first author supports Anne's attitude and enactment of participation by casting her in the role of critical participant in the project.

Anne has previously taken part in research projects. Most recently, she has signed up for a research project in the US (independent of any Danish hospitals) that studies her specific and rare heart disease. This involves giving a DNA sample. She follows the project's website and considers going to a scientific conference hosted by the project. By engaging in this particular project, she enacts hope for some future improvement of her own situation. However, with the prospect of a cure being very uncertain, her engagement can also be understood as a way of enacting the role of a 'curious and interested', resourceful, activist patient who raises her voice and tries to push the Danish healthcare sector towards more experimental practices. Anne is what we could call a 'biomedical pioneer' (see also Epstein, 1996; Rose and Novas, 2003).

In the user test, Anne explicitly acknowledges that what is taking place is going beyond normal practices; she treats the user test as an experiment and expects little from the concrete interactions, but remains motivated to test possible future practices. She takes an interest in the project itself, and asks about the project background, management and results. Two general conditions seem to contribute to her experimental attitude, which is shared by patients with otherwise different tactics: the transparency in the project regarding technical problems and the participating clinicians' inexperience. By being flawed, the system remains an open, experimental arena for participation. Additionally, all involved are 'beginners' in using the system; as a result, a kind of 'shared pioneering' is facilitated.

*Insider and representative.* For Anne, the idea of taking on 'homework' and producing information is not foreign. She already handles several tasks and devices related to her heart disease at home, such as manual transmission of ICD-data, self-monitoring and medication management. Being engaged in the material participation that keeps chronic care infrastructures (Langstrup, 2013) running is part of her daily life. On the one hand, she is content with these practices, as she feels confident and in no need for consulting clinicians, due to her own professional background as a home-care assistant. On the other hand, she misses being followed more closely by a cardiologist, and feels that she has somehow slipped out of the system. She characterizes her own attitude as being more critical of medical authorities than other patients, because of her general skills, professional qualifications and position as an 'insider' of the system.

Anne's pragmatic yet experimental attitude also shows in her use of P-Record. Pessimistic about her own situation, but still curious to try out new practices, she raises a concern using the preparation form, although she has no expectation of receiving a response, as she has prior knowledge that the issue is clinically insolvable. During the following consultation, she actively engages in the use of P-Record, initially by referring to the issue she has raised, but then shifting focus from her own situation to assisting the clinician in maneuvering in the system and commenting on his working conditions in the situation:

Mark has finished checking Anne's ICD and only now turns to the screen to look at her entries in P-Record. Anne gets up from her assigned chair in the opposite corner of the room and stands behind Mark, looking at the screen over his shoulder. 'Should I write a message?' Mark asks me (the facilitator). Anne jumps in: 'You could do that if there was something to note', she suggests. An error box occurs, preventing Mark from clicking on the message function. 'Apparently it wants you to shut down the logbook too', Anne says, and while Mark is trying to open the message box, she continues: 'You could just write hi'. Mark looks at me as to apologize for his confusion: Due to lack of staff today, he is overloaded with work. 'Actually, I was to do an ablation (surgical procedure) and then this, right, and suddenly I also have to do another follow-up', he says with frustration. 'Who's doing your ablation now then?' Anne asks in a concerned tone. (Field note, in-clinic follow-up with Anne and the technician, Mark)

The situation above shows how Anne enacts participation in both research and her own care as an activist mediating patients and professionals: She establishes a position as both a 'healthcare insider' and 'patient representative'. This brings us back to the opening situation, in which Anne is evaluating P-Record's social network, which displays her way of representing and caring for other patients first and foremost – in the user test and in general. Anne is engaged in patient organizations as a patient-to-patient advisor. Moreover, she follows two Facebook groups of heart patients. One is for Danish ICD patients, and she describes her use of this group as primarily a way of educating herself as an advisor by staying updated on common concerns and new treatment options. She perceives herself as more 'serious' than most members of the group; she is annoyed by the purely social exchanges and rarely writes anything herself. In following the second group, an international patient group focused on sharing new knowledge regarding her specific heart disease, she is, to a larger degree, acting out of concern for her own situation. However, since Anne realizes that any future treatment advances probably will not be in time to benefit her, her engagement also seems to be driven by a motivation to bring about change for other patients and in the Danish healthcare system at large.

As a participatory device, P-Record is but one of the tools with which Anne engages with these larger issues and collectives. Enabled by existing tools and sociotechnical infrastructure at hand (her computer, the internet and patient forums), Anne is already participating vigorously in issues related to her own and other patients' treatment even before being invited as a user of P-Record. She seizes the opportunities embedded in the project, but is not dependent on P-Record as 'an act of institutional generosity' (Marres, 2012: 138) to be a participant. Using P-Record to experiment and push for change beyond her own situation, Anne seizes the invitation to take part in research. However, aware of

the ‘politics’, hierarchies and working conditions in healthcare, she has no expectations of entering an equal collaboration: With a critical stance – and personal distance – she enacts an activist tactic. As a result, Anne seems better able to handle the ambiguity of the invitation and stay clear of disappointments than other patient-users. One such patient-user is Ben, who we will meet next.

### Partnership

Like Anne, Ben is eager to enter a shared project of sparking change, but with higher expectations and a very different participatory tactic. Ben has had his ICD for eight years, but is still trying to come to terms with its impact on his daily life. This includes having to navigate through a distributed care scheme that, in his experience, lacks coordination and fails to give him concurrent answers. With this background, Ben participates in order to become an entrepreneurial partner. He has high expectations of P-Record and, subsequently, experiences a huge disappointment. His attitude is characterized by a willingness to take on responsibility, if he can get a ‘place at the table’ where decisions are made and if he in the end will get something out of his investment – a *quid pro quo*. In other words, Ben seizes the invitation to collaborate as an equal partner and resists the parts of P-Record’s script that imply being either solely an information provider or an independent self-manager. This attitude resonates well with neo-liberal parts of e-health innovation narratives that foreground the patient as a user-entrepreneur who can disrupt ineffective and entrenched structures (Christensen et al., 2000; Von Hippel, 2005).

*Let’s try something new!* Ben, first of all, describes his motivation for participating in the user test as a matter of always being ready to try to do things better:

I’m always in for something new, exploring new things. ... And I think there’s a challenge here. For instance, in elderly care where they use online tools to talk and so on. And what if you received a text message when you had to go to the doctor – it doesn’t cost much and it’s done automatically. These are cheap solutions. It annoys me when people don’t show up – it’s expensive labor when people [the staff] have to wait for those who don’t show up. (First interview with Ben)

This way, Ben links his motivation to participate with his concern for the provision of welfare services and his interest in contributing to creating solutions. As such, he already sees himself as part of a broader societal collaboration. He positions himself as a responsible citizen who cares for the healthcare system; for him, becoming a participating patient and research subject through the user test is, most importantly, an extension of this civic commitment.

During the user test, Ben actively engages in solving technical problems and proposes additions to the design, such as spelling control, automatic warnings, and document upload; he thereby acts as co-designer and project partner. In doing so, he seizes the invitation to participate in a transparent experiment, in which the first

author and the clinicians tinker with the process, system and practices, as they go along. Overall, Ben treats the user test as a partnership, in which he participates with enthusiasm and initiative. At one point, he tells the cardiologists at another hospital, where he works in a service function, about the project and tries to establish a contact between them and the first author. Likewise, concerned with how his perspective will be heard, he suggests a workshop where patients can discuss the system together with leading clinicians and the designers. Throughout the user test, he challenges the project's timeframe and does not readily accept having his partnership terminated as the project comes to an end.

*Bridging the gap.* In addition to societal concerns, Ben's motivation to participate in the user test seems to rest in the hope of improving his own care. From the beginning, he enrolls the first author in the infrastructure of his care, as someone who might help sort out the problems that he is currently facing. These include technical issues with the telemedical setup, medical issues regarding his blood pressure and lack of coordination between the local heart clinic and his GP. The way Ben initially uses P-Record illustrates this:

Before the first in-clinic follow-up, Ben writes a request for a 24-hour blood pressure monitor in P-Record, since he experiences variations that affect his ability to work. He also writes a message to me (the facilitator), with the contact details for a cardiologist at the local hospital to whom his GP has referred him regarding his blood pressure, but who has not yet called him in. At the in-clinic follow-up, he draws the cardiologist's attention to his writings and further presents her with the referral letter. She briefly tells him to take it up with the local hospital since it has nothing to do with the device follow-up. Afterwards, Ben is irritated and refers to the situation as typical: 'What's needed is collaboration, and that's what I often miss'. He repeats an earlier suggestion to enable upload of documents in P-Record and asks me if I can contact the local hospital and clear things out. (Field note, preparation and in-clinic follow-up with Ben)

First, Ben's call for collaboration related to his care is an expression of frustration with current practices, which he sees as characterized by deficient communication and coordination between various clinicians. The task of mending the gap by carrying information between clinics and pushing for action (for instance having a 24-hour blood pressure monitor) is not easy for him and does not lead to the results that he hopes for. Second, his call for collaboration also expresses his wish to take part – to be a partner and an engaged lead-user. Besides trying to figure out and tie the ends in the care infrastructure, he takes on an active role in his own care by reading up on medications and measuring his pulse and blood pressure. However, Ben does not experience this as paying off; from his point of view, his knowledge and data are not sufficiently included or acknowledged in the medical decision-making. P-Record's invitation to participate and promise of supporting him in 'bridging the gap' briefly sparked hope for immediate change. Yet despite Ben's efforts to respond to the invitation, nothing improves. In his first attempt, he targets the wrong receivers – the device cardiologist and the facilitator. In his second attempt, with the preparation form for the consultation at the local hospital, the cardiologist responds

with reservations to Ben's request for a blood pressure measurement as well as to his question regarding an over-the-counter drug that he has done some research on.

Ben's partnership tactic is, by and large, in line with P-Record's invitation to participate. It also reproduces at least one of the ambiguities of the invitation: Ben's use of P-Record cuts across research and care and, at times, adds to the obscurity already built into the user test. This does not, in itself, cause trouble. However, since Ben seizes the invitation to become a partner in *both* innovation and care, he is highly disappointed when the user test only emphasizes the existing challenges of distributed care without facilitating immediate change for himself. In innovation parlance, lead users get 'return of investment' on their engagement by getting the use-value of better products (Von Hippel, 2005). Here, the partnership – whether innovation or care-related – turns out to involve less equal and mutual commitment than Ben expected. His creative tactic remains just that – individual maneuvering in a space delineated and structured from elsewhere, as de Certeau (1984) would see it. However, the participation-oriented reality focused on capitalizing on users' input through innovation is different from the one described by de Certeau, where users are distinct in that they are exactly those who clandestinely produce *without* capitalizing (p. xx). The recognition of and vision to mobilize the creativity and knowledge of users promise a blurring of the boundary and distribution of power between maker and user but those promises ring hollow to participants, when contributions are not recognized. Marres (2012) suggests that in such participation-oriented realities the challenge to establish relations of relevance is serious and the 'burden of relevance' may not be equally distributed (p. 140). What Ben finds relevant – genuine collaboration – and seek to enact in his experiments with P-Record is not being recognized as relevant acts of participation by other, more powerful actors, leading to disappointment with the participatory capacities of the technology.

## Compliance

In our last case, we illustrate a participatory tactic that, in its subtlety, might escape conceptualizations of patient participation that underline partnership and active engagement, like the ones informing the project behind P-Record, however sensitive to invisible forms of patient work they may be (e.g. Unruh and Pratt, 2008):

Leo and I are waiting at the device clinic for his in-clinic follow-up. In the corridor, we meet the project nurse, who he knows from another research project and expresses a personal trust in; she is welcoming but also hasty. During the follow-up, the technician and cardiologist take their time to discuss the system. Leo is involved in the conversation, yet most of the time he remains a spectator. His reticent attitude is underscored by the way the technician – without much success – tries to involve Leo in speculating about the future potential of P-Record. The cardiologist thanks Leo for his efforts and, admittedly ironically, praises him for being 'a good patient', as he has done his homework with P-Record. The visit ends with other hospital staff brusquely asking us to leave the room – we have occupied it for too long – and Leo making apologies. Despite the awkward closing, Leo is still up to completing the rest of his tasks in the user-test – with a little instruction and encouragement from my side. (Field note, Leo's visit to the device clinic)



In this situation from the user test, we meet Leo. Most of all, he participates out of a sense of duty – towards the care scheme, society and fellow heart patients, and anchored in a general acceptance of authority. His attitude is characterized by a willingness to participate, if it can help others or calm his relatives, or as part of fulfilling a contract with the healthcare system. He tries to keep his engagement to a minimum – to merely comply and otherwise focus on other things than those that relate to his heart disease, be it care practices or research projects.

*'If it can help you'.* When initially presented with P-Record and the user test, Leo is hesitant. He draws his own eligibility as a participant into doubt, calling himself 'a rather banal case' – he 'has no problems or anything else to write about'. Although he ultimately agrees to participate, he continues to express doubts about the value of his participation – unsure if he 'can contribute with anything'. In a very direct way, he responds to the invitation to participate as it is inscribed in P-Record: he equates the extent of his contribution with the extent to which he uses P-Record rather than his overall participation and deliberations in the project. Yet, he goes on participating by complying with the project protocol: He fills out preparation forms for follow-ups, calls the first author for instructions (as he wants to do it correctly), and shows up for extra consultations at inconvenient hours. From the rationale that 'if one can help others', he seems to put aside the feeling of not being able to respond to the invitation to become an information provider and, instead, responds to the invitation to participate in a research project, despite its seemingly more obscure purpose (as assessed by him).

*With reason: Balancing duty and good sense.* Leo has had his ICD for three years and been a heart patient for ten years, starting with a heart attack. He was talked into getting the ICD by his wife and the cardiologist, and when asked if he is happy with it, he refers to the authority of the doctors: 'If they think it is good for me, then it is'. His current situation is characterized by routine and stability. Describing himself as 'feeling alright', adding 'under the circumstances', Leo takes on a pragmatic, modest attitude when coping with his situation. Overall, Leo is content with the care he receives. In all his years as a heart patient, he has had the same cardiologist at the local hospital, and his trust in the care scheme partly seems to rest on this continuity and the quality of their relationship. He does not ask a lot and is fine with 'not always being told everything'. However, Leo actively takes on the job as information courier by making sure to have tests done at the heart clinic before upcoming appointments with his GP, and bringing the results with him to those appointments. He does so not from anxiety – he trusts 'them' to react if something is not right – but for sake of convenience, as well as to spare the system of double work. He is likewise content with the remote monitoring setup: While he did not mind going to the clinic often, he feels safe and recognizes that this is easier for the clinicians. Besides attending consultations, doing ICD-transmissions, and managing medication, Leo spends as little energy as possible on his illness and treatment – focusing on it 'only makes you ill'.

The way that Leo uses P-Record during the user test mirrors his general tactic as a patient. He fills out the preparation form, but his writings are sparse: Unless 'there is really something to write about', writing 'serves no one', he explains. The little he writes

is for the sake of the research project and, likewise, he agrees to the remaining test activities, including interviews, since we need it to 'become wiser'. In the end, he evaluates the system in terms of its usability and overall meaningfulness: On both parameters, it fails to be something for him. He also links this to being part of a generation that is not used to computers and the kind of interactions computers facilitate. Browsing through the social network, he expresses respect for some patients' need to share, but has no interest in using this feature himself. Leo regards his illness as a private matter and does not take active part in any kind of patient networks, as he imagines that social activities will end up in 'talk about the heart'. As a typical example of the way he tries to find a balance between his sense of duty and his wish not to grant illness too much attention, he is a member of the heart association, but 'only gives some money'.

The challenge of finding a reasonable way of being a patient embedded in the social structures of patient communities also frames Leo's participation in other research projects. Seen from his perspective, participation has had varying success. One project at the heart clinic gave him access to a rehabilitation program, with which he was very pleased; another project at the device clinic provided increased personal contact and continuity, thanks to a dedicated project nurse. But a third project, conducted by a pharmaceutical company, caused frustrations when neither his own data nor the overall research results were conveyed to him, and he opted out. Leo is willing to help out, even when he does not immediately recognize potential value, but there needs to be fairness. By taking on the task of providing information, for clinical or scientific purposes, he enters a reciprocal relationship. He participates in practices that he expects to be founded on an unspoken contract of reasonable exchange. While he seeks to comply with medical authority and contribute to a broader community, his motivation drops when the counterpart does not enact the same sense of decency.

Leo's participatory tactic as a compliant patient and citizen allows him to respond to P-Record's ambiguous invitation to become a participant without subsequent disappointment. He is not interested in voicing particular concerns, but rests assured that, for the most part, the concerns of the experts will be adequate for bringing on relevant change. As he shifts orientation from responding to the invitation to become involved in his own care in a new way (as information provider or self-manager) to simply respond when called upon to 'help out', participation becomes meaningful. Thus, he becomes a user and participatory patient after all – but just for the occasion.

## **The politics of participatory technologies**

As Marres (2012: 141) has recounted in her analysis of participation in environmental politics, technology is often cast as tools that make participation 'easy'. Equally in health care, e-health has been promoted as the devices per se for involving patients, empowering them and putting them 'in the driving seat' of health care (European Commission, 2012). In this article, we have suggested that while technologies do shape what becomes issues of relevance in participatory practices, this is far from a straightforward accomplishment. In the case of the user test of P-Record, the patient-users were faced with an invitation that framed participation as collaboration in both a direct and indirect manner, and further obscured the purposes of participation by

simultaneously inviting patients to take part in research and care. With this built-in ambiguity, P-Record – for better or for worse – materialized and mediated an overall participatory strategy in healthcare that proposes to serve a multitude of ‘projects’ and, by definition, involves a prescription of taking part, though leaving it relatively open how to do so.

Conceptually, this ‘soft strategy’ of participation poses a challenge to the traditional view of disciplining technologies, in that users’ creative ‘tinkerings’ are – at least in principle – welcomed and deemed necessary to the very workings of the phenomenon. Introducing the concept of tactics of material participation (De Certeau, 1984; Marres, 2012), we have sought to develop alternative analytics that make it possible to register normative variations among the responses to the discursively open, albeit materially inscribed, invitations to participate in matters of healthcare. We have followed Marres’s suggestion to bracket participation as an ideal and instead interrogate it as an object of inquiry. We have sought to invoke de Certeau’s interest in the creativity and politics of everyday life, where people use, manipulate and tinker with (see Mol et al., 2010) the strategies they meet. We recognize that theoretical tensions exist between our two main sources of inspiration, most notably on the issue of agency. De Certeau’s (1984) human users are both weak – he calls tactics ‘the art of the weak’ – and powerful in their subversive use practices, but they act autonomously (p. 37). Marres (2012), on the other hand, works from a relational understanding that places agency at the level of the assemblage of devices, settings and humans that together perform participation. In our view, de Certeau pays too little attention to the active role of the material and, furthermore, has a too-romanticized view of users as acting to counter power. In the context of our case, this view rests uneasily with the increasing capitalization of user-knowledge (e.g. Bason, 2010; Von Hippel, 2009) that can be said to co-opt the resistance of users (Bogner, 2012; Wehling, 2012). Still, adding to Marres’s material-semiotic approach explicit attention to users as political and creative actors allows us to highlight the implications of the kind of ‘soft’ strategy that an invitation to participation is, and subsequently to reflect critically on invited participation, as it takes place in our case and in contemporary healthcare more broadly. It is not without importance to recognize that, as participatory devices, e-health technologies are currently politicized when promoted as having certain normative capacities that make patients active in a way that is beneficial, first and foremost, for patients themselves, but also for ‘the greater good’ of the welfare state. De Certeau’s critical perspective also helps us recognize resistances located in the tactics of participants. The norms invested in technologies do not remain unchanged, and the actual forms of participation facilitated by, in this case, e-health technologies must necessarily be studied in, and as, practice.

## **Conclusion: Normative variations of material participation unfolded**

What have these suggested analytics taught us about the participatory practices facilitated by P-Record? Overall, becoming users of the participatory device, P-Record, involved dealing with ambiguity and creating relevant projects to pursue. As we have shown, the patients did so – with varying success – by employing different

tactics. With an *activist* tactic, Anne responded to the invitation to participate in research; from the onset, she handled the ambiguous invitation by focusing on a distanced ‘project’ with more abstract outcome criteria. While she endorsed a role as participatory patient and actively used the participatory device, she did so to give voice to and push for change for a larger community of patients, rather than to collaborate in (reconfiguring) her own care. Within this at once pragmatic and ambitious orientation, material participation through P-Record became meaningful despite failing to lead to the promised outcomes in care. Likewise, practicing a tactic of compliance allowed Leo to reorient from his own care to a larger project. At first, the entanglement of research and care made Leo hesitant toward the invitations to participate: Not finding it meaningful to become an information provider, he saw himself as an ineligible participant. However, Leo’s attitude as a compliant patient and citizen led him to answer the invitation, but with what we could term a fragile engagement resting on balanced interpersonal relations only, which made him an unlikely long-term user of the specific participatory device. Ironically, P-Record’s ambiguous invitation proved most problematic for the patient-users who responded directly to the offer to collaborate. Ben participated as an entrepreneurially oriented partner, but this meant that when P-Record had no return on investment for him as a lead user, engagement led to disappointment and great frustration. Finally, it should be noted that no patients opted for the (in theory, possible) tactic of using P-Record as a device for ‘their own’ independent self-management, the individualized version of participation as diminishing the use of healthcare resources, which sometimes surfaces in discourses of e-health (Petersson, 2012).

Among the different normative variations of material participation as enacted through P-Record, the ones that entailed collective projects rather than individual ones – pushing for better care for heart patients, promoting societal innovation or performing civic duty – seemed to be experienced as more successful and meaningful among participants. It proved much more difficult to align expectations when it came to individual projects and concerns. On the one hand, this tells us that the promise of putting ‘the patient in the driver’s seat’ through participatory e-health technologies may prove difficult to deliver if we think of the patient as an individual. On the other hand, and on a more positive note, it may reassure those who see mainly individualization and tokenism in e-health’s participatory future. Our case suggests that patients are concerned with larger collectives, and mobilize the tools they are given to these ends. This, however, challenges e-health protagonists and participatory entrepreneurs – such as ourselves – to be aware of and sensitive to the unforeseen answers and alternative collective ‘projects’ arising in a participatory-minded healthcare system that has set its mind on equipping and inviting patients in new ways.

As a final note, we wish to underscore the importance of also considering the patients who either totally dismiss the invitation to participate or never get the chance because they do not fit the inclusion criteria (in the case of P-Record, for instance, by having insufficient Danish skills). Here, as in other parts of participatory-minded healthcare systems, inclusion in the collective is far from complete. Analytically, it makes sense to speak about non-participation in such cases of total exclusion. That being said, our analytics are intended to and make it possible to recognize even the

subtlest or most ‘unruly’ answers to invitations to participation as, indeed, participation. This is both a political and a heuristic move: Understanding and unpacking patients’ tinkering with participatory devices as participation is, if not an act of empowerment, then at least a way of recognizing the creative power that rests in otherwise very different manifestations of participatory agency.

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## Notes

1. In an earlier paper (Nielsen, 2015), the first author exploited the user test in a more classic way, to explore P-Record’s specific participatory capacity for involving patients as information providers, zooming in on P-Record as a participatory information and communication technology and on concrete use practices.
2. This and all other untagged quotes integrated in the text are direct quotes from the user-test (text boxes and users’ entries in the system; informational material; and transcripts of interviews, instructions and clinical encounters).

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